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ABSTRACT

This packet of materials focuses on the self-advocacy of individuals with disabilities. Part 1 includes: "Self-Advocacy: Speaking for Yourself" (Michael Kennedy and Patricia Killius), an article written by individuals with disabilities that discusses the importance of people with disabilities making their own decisions and having a say about the services they receive. Strategies for starting a self-advocacy group and the benefits of such a group are described. Part 2, "Resources on Self-Advocacy" (Rachel Zubal, Bonnie Shoultz, and Pam Walker), lists self-advocacy materials that are currently available. Included are resources on choice and self-determination in which the voices of self-advocates were included. Part 3 includes the following articles that all address the need for individuals with disabilities to advocate for themselves and the growth of the self-advocacy movement: "Self-Determination" (Michael Kennedy), "Thoughts about Self-Advocacy" (Michael Kennedy and Bonnie Shoultz), and "More Thoughts about Self-Advocacy: The Movement, The Group and the Individual" (Bonnie Shoultz). (CR)

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MATERIALS ON SELF-ADVOCACY

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THOUGHTS ABOUT SELF-ADVOCACY, by Michael Kennedy, with Bonnie Shoultz (reprinted from TASH Newsletter, 22(4), 27-28.)

MORE THOUGHTS ABOUT SELF-ADVOCACY: THE MOVEMENT, THE GROUP, AND THE INDIVIDUAL, by Bonnie Shoultz (reprinted from TASH Newsletter, 22(10/11), 22-25.

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SELF-ADVOCACY:

SPEAKING FOR YOURSELF

by Michael Kennedy & Patricia Killius

(Recorded and Edited by Deborah Olson, 1986)

As self-advocacy coordinators at the Center on Human Policy, we speak to professionals, parents, and the general public to tell them that disabled people have rights. We want them to know that we can make decisions and speak out for ourselves.

We also teach people with developmental disabilities and mental retardation that they have the right to self-determination and to live as independently as is possible for them. Both of us lived in institutions for years, so we know what it's like for others.

One way we do this is to facilitate self-advocacy groups. In these groups, people like ourselves learn to speak out for themselves. People with all kinds of disabilities participate in the groups. Some of them still live in the institution, but most live in group homes, supportive apartments, with families and even independently.

In July, 1985, we held the first New York State conference of self-advocacy for people with developmental disabilities. The purpose was to give people with developmental disabilities the chance to speak out about their rights and the things they want to see changed. We also wanted professionals to see that we have a voice of our own. We want the same rights as everyone else. Nothing more, nothing less.

Definition

Self-advocacy means people with developmental disabilities speaking up and speaking out for their rights. For people who can't speak, it may mean having someone interpret what you want to say. People with developmental disabilities should have the right to speak up and teach other people about their rights. We won't always have someone to look out for us.

People need to listen to what we want even though they might not want to. Speaking out can be taking a risk. Sometimes you're afraid a staff person might say no.

Some People Can't Speak for Themselves

Some people can't talk or communicate easily with others. Other people may be really shy or uncomfortable talking. This shouldn't mean they can't be part of everyday life. Someone with a severe disability can still live a good life in the community even though they can't express themselves very well or communicate their wants clearly. They may need a friend who can speak for them. The best spokesperson for someone who can't speak may be another person with a disability who can speak, maybe a friend of that person. Another disabled person knows where that person is coming from; they've had similar experiences. Professionals may say they understand, but in reality they haven't lived as we have and haven't had the same experience.

> MIKE: Ted and I were in the same institution together many years ago. When we met again recently I could still understand him, even though he has really difficult speech and it's hard for other people to understand him.

PAT: Even for someone who can't speak at all, another person who's disabled is still a good spokesperson just because you know what it is like to be a consumer or to live in an institution.

Self-Advocacy is About Having Choices

Living in the institution you don't have the freedom to make choices. You are told what to do, for example, when to eat, when to sleep and when to get ready for work.

You have no choice about going places when the whole unit is going someplace. You can't go out on your own.

MIKE: Now I can do things with other people or by myself if that's what I want. At least I have a choice.

Self-advocacy, or speaking for yourself, is a big part of living in the community. People with disabilities who live in the community should have the right to make their own decisions, just like anyone else. For example, we should have the choice of who we want to work for us. In our apartment, the director will interview a person who wants to work with us. Then she will bring them to the apartment and have us interview the person. We ask things like, "Have you ever worked with disabled people before?" "What kind of recreational things do you like to do?" We ask this so that we can get a good idea of what they like to do and if we like the same thing. We also ask how they feel about transferring someone from one chair to another. We ask to get an idea of how they feel about being with us.

After these questions, the person asks questions of us. We'll give them answers about where we work and what we do.

The following day we get together with the director and talk about that person. She takes our ideas to the board of the agency and the board usually approves who we recommend for hiring.

The choices you should have are choosing your own friends and having your friends come to see you, going to the church of your choice when you want to go, deciding whether to have a real job instead of working in a sheltered workshop or activity center, and lots of other choices. Sometimes people with developmental disabilities need help making choices, or even knowing what their options are. Parents, staff, and friends can help people learn about choosing, if they pay attention to the person.

Self-Advocacy Means Having a Say About Your Services

People with developmental disabilities can and should have an impact on services by participating in agency boards and councils. It's important that we share our ideas because we use some of the services. Many of us have been getting services from agencies all our lives. We know that some services are good because they try to meet our individual needs. We also recognize that some services are bad because they don't integrate people in the community and they don't provide programs to help us become more independent. We can tell agencies what kind of things we need to live and grow in the community. But it's not enough to have just one consumer on a board.

If there are several with different disabilities or different experiences, providers will know more about your needs.

When we first got our self-advocacy jobs a lot of agencies asked us to be on their boards. They didn't seem to be aware of other people with disabilities who could also speak on their programs.

> PAT: The same two consumers shouldn't be on all the boards in the community, because they're going to get tired of hearing from us. There are other consumers who would learn a lot from the experience and also contribute to the board.

People with disabilities might need special supports to be on a board. For example we might need aides to help us get to the meeting, to help us with personal needs, for writing and reading, for speaking for someone who can't speak or interpreting for someone who can't hear. It's important to have this support so that we can participate on the board. Without this support we're just a token.

Learning About Self-Advocacy

All disabled people have the right to learn to speak for themselves. It's important because there will be a day when our parents won't be able to speak for us. Disabled people can teach each other how to speak for themselves. Role-playing a variety of problems or situations is a good way to learn self-advocacy.

There's more strength in forming a group. One individual speaking out is easily over-looked. If you have a group of people who want the same thing, you have a better chance of people listening.

This is what we did in Syracuse. We drew up a list of friends and other people we knew. We told them about self-advocacy and asked them if they wanted to become involved. That's how we got started.

We brainstormed some issues and talked about issues at every meeting. For example, we talked about transportation problems and education.

To teach ourselves about our rights we used a tool called Rights Now! It contains cassettes, pictures and a slide show about different people in situations learning about self-advocacy. For instance, finding meaningful work instead of sheltered employment, finding time to be alone with your friends, or working out compromises with the people you live with. Rights Now! is not available any more, but you might be able to get it from your state's Protection and Advocacy agency.

Ways to Start a Group

We started our groups through the College for Living, but not everybody has to do it the same way. There are many ways to start a group. First, you have to find a good place to meet. It should be easy for everyone to get to it. Then you have to make a list of people to be a part of the group. It's OK to start small. You have to let people know about the meeting either by calling them or seeing them at work or where you live. You have to agree on a meeting date and time that would be good for everybody.

When you have your first meeting, you have to be sure that everyone feels comfortable. You should have people introduce themselves and maybe say why they wanted to learn about self-advocacy. You may have to explain about self-advocacy first. If you decide to use the Rights Now! material, you'll have to tell them about the cassettes and pictures. Or you could show a film, like the People First film, or a slide show, like Our Voice Is New (which we helped produce) about self-advocacy. After the film or slides you can talk about some of the issues, like speaking out, having someone speak for you if you can't speak well, or what it feels like to be labeled mentally retarded.

We and the people in our group think that it is good to form a group because:

1. People aren't always going to be around to make decisions for you, you have to learn to make your own decisions.
2. You can learn about each other, everyone has different needs.
3. You can work together for new opportunities for people with disabilities.
4. You can learn about your rights as a citizen.
5. You can help other people who can't speak.
6. You can have fun by meeting other people.

By speaking for yourself you make other people--group home staff, government officials, and the general public, see that you are a person just like them, not a "disability." Self-advocacy is a part of living in the community. Without it we might as well be shoved back into the institution.

RESOURCES ON SELF-ADVOCACY

Compiled by Rachael Zubal, Bonnie Shoultz, and Pam Walker

June 1997

The self-advocacy movement is growing and producing many materials on and by people with disabilities speaking for themselves. This is a partial listing of self-advocacy resources currently available. We have included a few items on choice and self-determination, which is related to the development of self-advocacy, in which the voices of self-advocates were included.

CENTER ON HUMAN POLICY RESOURCES

The Disability Blanket, by Michael J. Kennedy. (1994) This article represents the experience of how it feels to be under a one-size-and-fabric-fits-all blanket, and offers a vision for change.

Our Voice is New: All About Self-Advocacy. (1986). A slide presentation with script and cassette tape describing what self-advocacy is, why it is important, what self-advocates work to achieve, and how to get started as a self-advocate.

A Chance To Be Made Whole: People First Members Being Friends to Tear Down Institution Walls. (1997). This booklet is the summary of a meeting of People First of Tennessee members and advisors complied by John O'Brien. It presents, in their own words, what people have learned about reaching out and being friends to people who still live in institutions, and about supporting them as they move out into the community. Their hope is that other self-advocacy groups can learn from their experiences on institution closure.

Available from:

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280
1-800-894-0826 tty 315-443-4335 fax 315-443-4338
E-Mail: thechp@sued.syr.edu
URL: http://soeweb.syr.edu/thechp/

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SELF ADVOCATES BECOMING EMPOWERED RESOURCES

Open the Doors: The Nuts & Bolts of Building Supports for Each Other, a publication by Self Advocates Becoming Empowered, the national organization on self-advocacy, funded by the Joseph P. Kennedy Foundation., describes the meaningful contributions that self-advocates are making throughout the United States.

Available from:

Tulsa Arc
16 East 16th Street, Suite 405
Tulsa, OK 74119-4447
(918) 582-8272

UNIVERSITY OF MINNESOTA RESOURCES

IMPACT: Feature Issue on Supported Living. August 1995. This issue describes supported living, giving numerous examples of agency approaches, and offering the perspectives of people with disabilities.

IMPACT: Feature Issue on Consumer Controlled Housing. Spring 1990. This issue focuses on concerns, strategies, and options in consumer controlled housing for people with disabilities, including resources for financing housing in the community.

IMPACT: Feature Issue on Institution Closure. Winter 1995/1996. This issue contains information on national trends as well as a variety of articles on closing institutions written from the perspectives of self-advocates, professionals, parents, researchers, and policy makers.

IMPACT: Feature Issue on Self-Advocacy. Winter 1990/1991. This issue focuses on self-advocacy for persons with disabilities, and includes information on self-advocacy strategies and examples of its impact on lives.

IMPACT: Feature Issue on Self-Advocacy. Spring 1994. This issue focuses on the national self-advocacy movement, barriers and supports to self-advocacy, and the future.

Effective Self-Advocacy: Empowering People with Disabilities to Speak for Themselves. This report is a record of the discussion during a 1990 workshop which brought together 18 people from seven states who have experience in self-advocacy for people with developmental disabilities.

Available from:

Institute on Community Integration, University of Minnesota
109 Pattee Hall, 150 Pillsbury Drive, S.E.
Minneapolis, MN 55455
(612) 624-4512
E-mail: ici@mail.ici.coled.umn.edu
URL: http://www.ici.coled.umn.edu/ici/

BROOKLINE BOOKS RESOURCES

We Can Speak for Ourselves. (1982). By P. Williams & B. Shoultz. This book describes the beginnings of the self-advocacy movement in the United States and in England. Includes suggestions for developing self-advocacy groups.

The Beliefs, Values, and Principles of Self-Advocacy. (1996). This booklet talks about the beliefs, values, and principles of self-advocacy, and about the role of support persons. It also gives examples of good practice. It is produced by the International League of Societies for Persons with Mental Handicap (ILSMH) Committee on Self-Advocacy formed to help promote self-advocacy internationally.

New Voices: Self-Advocacy by People with Disabilities. (1996). Edited by Hank Bersani and Gunnar Dybwad. This book includes many chapters written by self-advocates concerning the self-advocacy movement, and provides a historical perspective, as well as reflections on the current status and future course of the movement.

All available from:

Brookline Books
P.O. Box 1047
Cambridge, MA 02238-1047
1-800-666-BOOK

PAUL H. BROOKES PUBLISHING CO. RESOURCES

Self-Determination Across the Life Span: Independence and Choice for People with Disabilities, edited by Deanna J. Sands & Michael L. Wehmeyer. (1996). This book recognizes that self-determination is one of the building blocks of independence for people with disabilities and explores the theoretical, developmental, and practical aspects of decision making.

Self-Determination and Trust: My Experiences and Thoughts, by Michael J. Kennedy. (1996). In this book chapter the author discusses how he defines self-determination, how important trusting relationships are in self-determination, and how the service system can support it. In **Self-Determination Across the Life Span: Independence and Choice for People with Disabilities**, edited by Deanna J. Sands & Michael L. Wehmeyer.

Available from:

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285
1-800-638-3775
E-mail: custserv@pbrookes.com
URL: http://www.pbrookes.com

THE ARC RESOURCES

Self-Advocacy Bibliography. This detailed bibliography lists several resources on self-advocacy. Single copies free, if requested.

Available from:

The Arc
500 East Border Street, Suite 300
Arlington, TX 76010
(817) 261-6003
E-mail: thearc@metronet.com
URL: http://TheArc.org/welcome.html

THE ROEHER INSTITUTE RESOURCES

The Power of Language (1996). Self-advocates, leaders of the campaign to promote use of plain language, designed this creative workshop to help people improve their writing. The Handbook informs about principles of plain language. The Facilitator's Guide shows how to run a Power of Language Workshop. The workbook includes notes, exercises and examples for workshop participants. Ideal for anyone who wants their writing to be accessible to more people.

Advice for Advisors: People First. (1988) by Bill Worrell, Written by People First, a handbook for those who act as advisors to self-advocacy groups. Explains what self-advocacy is, how to make it work, the People First movement, empowerment and qualities of a good advisor.

Leadership Training Manual: People First (1987). By Bill Worrell. Designed by People First for those who want to know what the organization represents and how to start and operate their own group. Contains illustrations as well as step-by-step guidelines for members, leaders and advisors involved in self-advocacy.

Available from:

Roeher Institute
Kinsmen Building, York University
4700 Keele Street
North York, ON M3J 1P3
CANADA
416-661-9611 tdd 416-661-2023 fax 416-661-5701
E-Mail: roeher@yorku.ca
URL: http://indie.ca/roeher

OTHER MISCELLANEOUS RESOURCES

SELF-ADVOCACY ORGANIZING

Self-Advocacy Organizing: A Manual for People with Disabilities. Outlines the step-by-step process of starting a self-advocacy group. A good resource for new groups.

To order, write to:

Massachusetts Coalition of Citizens
with Disabilities (MCCD)
20 Park Plaza, Suite 603
Boston, MA 02116
(617) 482-1336

TASH NEWSLETTER ARTICLES

The Value of Trust, by Michael Kennedy, prepared with the assistance of Bonnie Shoultz. This article offers a contribution in its discussion of how a person with a disability creates and manages trust in supportive relationships. Most other writing on relationships is from the perspective of an agency or a person providing support. TASH Newsletter, February 1995, pp. 24-26.

Self-Determination, by Michael Kennedy. The author talks about how at an early age he had to learn to speak up for himself and how the definition of self-determination has changed over time. TASH Newsletter, September 1993, p. 11.

The Self-Advocacy Movement: Opportunities for Everyone, by Bonnie Shoultz. This article offers a brief description of current activities in the self-advocacy movement, emphasizing opportunities available due to the growth of the movement in the last four years. TASH Newsletter, November 1994, pp. 24-27.

Thoughts About Self-Advocacy, by Michael Kennedy, with Bonnie Shoultz. This articles talks about self-advocacy, including issues involving basic rights, real choices, and the dangers of misunderstanding what self-advocacy is. TASH Newsletter, April 1996, pp. 27-28.

More Thoughts on Self-Advocacy: The Movement, The Group, & The Individual, by Bonnie Shoultz. This article discusses the contributions of and differences between individual self-advocacy, group self-advocacy, and the self-advocacy movement. TASH Newsletter, October/November 1996, pp. 22-25.

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URL: http://www.tash.org

TOOLS FOR CHANGE

This new video series is designed for facilitators working with small groups or experienced educators, and is flexible enough for people with a wide range of learning abilities. Current programs available include:

Self-Advocacy: Freedom, Equality, and Justice for All

This interactive video program explores the concept of self-advocacy as a tool for building self-determination skills and as an emerging civil rights movement for people with disabilities.

Shaking Off Stereotypes

This interactive, entertaining video program allows you and your group to experience the value of high self-esteem--to believe in yourself and to have a sense of your own worth and dignity.

Available from:

Advocating Change Together
1821 University Avenue
Suite 306 South
St. Paul, MN 55104
612-641-0297

MUSIC

Speaking for Ourselves Cassette. Contains the song, "Speaking for Ourselves," the unofficial anthem of the self-advocacy movement. Also available is a new song on the ADA.

Available from:

Speaking for Ourselves
One Plymouth Meeting, Suite 625
Plymouth Meeting, PA 19462
(610) 825-4592

COUNT US IN

Count Us In: Growing Up with Down Syndrome (1994) by Jason Kingsley and Mitchell Levitz. In their experiences growing up with Down syndrome, Mitchell and Jason tell us about themselves *in their own words,* and make a powerful and inspirational statement about the full potential of people with developmental disabilities.

Available from:

Harcourt Brace Trade Division
525 B Street, Suite 1900
San Diego, CA 92101-4495
(619) 619-6218

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CENTER ON HUMAN POLICY

Self-Determination

By Michael Kennedy

I really started to learn about self-determination when I went into an institution when I was five years old. I am one of four children and I lived in three different New York State institutions for a total of 15 years. In the institutions, I had to learn to speak for myself and the other residents because of the attitudes of the staff who worked there. Very early on, watching how people were treated, I decided that I would have to learn to advocate on my own behalf. It was hard at first because I hadn't had to do that until that point. Living in the institution is a totally different world from living at home.

The meaning of self-determination has changed for me over the years. When I was in the institutions, I had to make sure I got the basic care I needed, like my personal hygiene and three meals a day, so that was what self-determination meant at that time. There, the caregivers seemed to think people didn't know what they wanted or how they wanted it done. Now, self-determination means running my own life and directing my personal care assistants on how best to assist me in my personal care. Now, people treat me like a human being who knows what he wants and who needs support to live his life. They ask me what I want and how I want it done. They also ask me what is the easiest way to get things done, so that I feel comfortable and they feel comfortable as well. So self-determination doesn't mean you have to do everything yourself, but it does mean you have to be in charge of your life to the fullest extent that you possibly can be.

It may seem like some people can't understand how to make decisions for themselves. I think that is because they have never had the opportunity to learn how to do it. If you've always been sheltered in terms of life experiences, you may not know enough to make the right choices about your life. If you've been told for years that you don't have the right to make choices, you will start to believe what you are told. It has to be confusing to people who have been told for years that they don't have these rights, and who are now told that they do. For example, when I first moved out of the institution and into a supported apartment setting, they told us we had the right to make choices. One of my roommates asked, "What's choices?" It's a shame, but that's how it was. When you live under an agency or an institution, they tend to think they know what you need without bothering to include you. And this is why so many people with disabilities feel that they can't make choices, because every time they voice their opinions, the staff or the agency or their parents disregard what they have to say and go ahead and do what they want to do rather than what the person wants.

What I consider to be self-determination for people with disabilities is to work collectively, with the person with the disability at the top. The person's family members, friends, agency staff, and anyone else the person wants involved become the collective, along with the person themselves. They make the decisions together, doing it *with* the person instead of having it all set up beforehand. Self-determination is *not* having everything done for you, because then you're not learning to do it for yourself. We have to be allowed to learn about life, make mistakes, and fall on our faces if need be. For example, I made a decision a couple of years ago to move to Georgia with my roommates. That didn't work out at all, and I felt like I had fallen flat on my face. But it really made me stop and realize that what I had before was better than I had thought it was, and I was fortunate to be able to come back and make a new life for myself. When I came back, I looked at things in a totally different light, and because of that my life is a lot better than before I left. One thing I learned is that you can't be afraid to ask for help when you need it. Asking for help is self-determination, too.

It is not self-determination when everybody makes your decisions for you, tells you where you are going to live, what house you can live in, what neighborhood you can live in, what clothes you should wear, what food you can eat, how much money you can spend and what you should buy. Why do people without disabilities feel that they have the right to become independent and self-determining but people with disabilities don't have that right? By not letting someone take a chance and experience life, professionals and parents make the biggest mistake they can make, because before a person becomes self-determining they've got to go through some trials and tribulations of life itself just like anybody else. Instead of doing everything for us and protecting us from life, people should just be available *if and when* we need help. And they shouldn't discard us if we don't want to take their suggestions, because we can't set up our lives like they set theirs up.

What people need to realize is that self-determination can be different things to different people. All people should have the opportunity to be self-determining, based on what that means for them. They might need some guidance, they might need some help, but that doesn't mean they ought to be shut out of opportunities to lead their life. Everybody needs some support at one time or another, I don't care who you are. What's important is to focus on what you can do, what you are good at and like to do. When you are getting supported, you have to take the initiative to tell other people what you want, what you need, and the supports you will need to live the way you want.

The Center on Human Policy has available a variety of reports and resources on community integration. For a list, please write to Rachael Zubal, Center on Human Policy, 200 Huntington Hall, Syracuse, NY 13244-2340 or call (315) 443-3851.

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Thoughts about Self-Advocacy

by Michael Kennedy, with Bonnie Shoultz

I give quite a few talks around the country on self-advocacy. Most of those talks are to service providers and parents, although there are some people with disabilities in some of the audiences. One thing that amazes me still is that although self-advocacy has been around for a long time now, since 1974 at least, there are some people who don't know anything about it. When I talk about it, they have a really surprised look on their face like it is a whole new world. Most people are very open to hearing about it, and I get requests to send more information about it from the people in the audiences. In this article I will talk about some things I want people to know about self-advocacy.

Here is what Self Advocates Becoming Empowered*, the new national self-advocacy organization, believes about self-advocacy.

We believe that people with disabilities should be treated as equals. That means that people should be given the same decisions, choices, rights, responsibilities and chances to speak up to empower themselves as well as to make new friendships and renew old friendships just like everyone else. They should also be able to learn from their mistakes like everyone else.

The self-advocacy movement was started by people with disabilities, especially people who had been in institutions and state schools, because they wanted their basic rights like everybody else. But before they could exercise their rights, they had to fight for the right to be heard and to have choices in their lives. They had to find out what basic rights they had, and then they had to begin to teach other people with disabilities, parents, and service providers.

...THERE IS ALWAYS A RISK FACTOR WHEN SOMEONE IS MAKING CHOICES FOR THEMSELVES, BUT PEOPLE STILL NEED THE OPPORTUNITY, EVEN IF THEY MAKE A MISTAKE.

Self advocacy is for everyone. Some people say to me, "It is fine for you to speak for yourself, because you aren't as disabled as my son or daughter, or the people I work with." I disagree with them. I say, "Have you taken the time to learn what that person wants or might need? Has the person heard about their rights? Is he or she facing an issue that they need support with? What can the person say for himself or herself, and how can you help him or her express more? Or are you just assuming that they want what you want for them?"

A lot of times I find that people have not taken the time to ask, and have just assumed they knew what was best for the person. I had one parent say to me one time that she always made the decisions because it was easier than figuring out how to help her daughter communicate. I said to her that I didn't know what her daughter's disability was, but there had to be a way that she could actively participate in the choices about her life.

WE ARE SAYING THAT WE SHOULD HAVE REAL CHOICES, NOT JUST THE CHOICES THAT OTHER PEOPLE GIVE US.

The first thing they would have to do is figure out a way for the mother and daughter to communicate with each other. Next would be to try to discover how the daughter could learn more about the choices she has, and then how she could make the choices. The daughter could be supported to make an informed choice of some kind, even one the mother might not make or feel totally comfortable with. This wouldn't have to be a big choice. We know there is always a risk factor when someone is making choices for themselves, but people still need the opportunity, even if they make a mistake.

When people tell me that I am "higher functioning" than the people they are talking about, I feel like they are telling me that I don't have anything in common with other people with disabilities. It's like they are putting me in a whole different category and saying that I don't have any right to speak. It upsets me because I take it that they don't want to give anyone else the opportunities I have been given, and that what I say can be ignored because they see me as more capable. It is a way of dividing us and putting down those who have more severe disabilities or who haven't had the opportunities to experience different situations in life.

Instead, they should be looking at how much each person would be able to offer if they were just given the chance to voice their wants and exercise their rights. For example, I recently visited a group home and heard a staff person say, "How do you like the way I decorated the house? The manager said I could do whatever I want." That told me that the residents didn't have a say in how their home would be decorated, when they could have been involved in planning and picking out the decorations. This is a simple example but who knows how things would look if the residents had helped with the decorating? And

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how will those residents learn to make other decisions if they can't be involved in how their home looks? I don't think she had even thought about involving them.

Later on she said to me, "We give choices." But even if that is true, it leaves the staff people in control.

The self-advocacy movement is here to say that things must be different. We are saying that we should have real choices, not just the choices that other people give us. Real choices means having the chance to choose the same things that other people, who don't have disabilities, have. No more and no less. Changing the words you use to refer to things is not enough. Calling everyone with a disability a self-advocate, or saying that everyone is given choices, are examples of just changing the words. To me, being a true self-advocate means being an active participant in a self-advocacy organization, speaking up for yourself, and making sure that your wants and needs are understood and valued. It also means understanding your responsibilities as a member of this society.

Self-advocacy has become popular, to the point that it has become a buzz-word that people use without really knowing much about it. Some of the dangers of that are that agencies can use the word to make themselves look good, or that people will pick a select few of us to be on every committee, to give testimony, and so on, without looking for other people with disabilities who might have something to contribute. Then they can say that they have consumer involvement, without really having it, because the same "consumers" are doing everything.

Another danger of not really understanding self-advocacy is that people outside of the movement, like parents or agency representatives or public officials, tell us what self-advocates should be doing. They are always saying, "You should testify about this," or "you should be working on that," without realizing that we need to decide for ourselves what we should be working on and how much time we can spend on what we choose to do. It is hard for us because most of us have been taught that we should please other people, not disappoint them by saying no. Often the advisors (these are people without disabilities who support us in our self-advocacy work) have to help us set limits and see that it is okay to set our own priorities.

The self-advocacy movement is international. There are organizations in Britain, Australia, New Zealand, Canada, Sweden, and other countries. There is a new book about self-advocacy all over the world, and I recommend it highly. It is *New Voices: Self-Advocacy by People with Disabilities*, edited by Gunnar Dybwad and Hank Bersani, Jr. It has chapters by people from each of the countries that I mentioned. They talk about their philosophies of self-advocacy, in their own words, and about its history in their countries. There is a whole section on the United States, but I believe it is also important to see how people in other countries think about it.

The common thread, to me, is that people with disabilities want a fair shake in life. We want the same things as everyone else. We don't want our lives controlled by systems and the people who work in them. We know that everyone has to follow some rules, but it is impossible to have a meaningful life if you are always controlled by other people. I recently wrote a chapter on self-determination (Kennedy, in press, pp. 45-6) where I talked about this issue in depth. I will quote some of the part where I gave suggestions:

"The system... needs to support the idea of teamwork and power sharing between people and their helpers. The system also needs to support the idea that people should be able to live how they want to, even if the professionals would live differently. The system is there to assist, offering guidance but not threatening us if we don't take the advice. This always means listening to us, really listening, and giving us feedback that is honest but respectful."

People involved in the self-advocacy movement help each other to advocate for things like power-sharing and system change. As a movement, we work on broad goals, like closing all the institutions in the country, but we don't forget the individual person with a disability who has problems in his or her own life. We support each other as much as we can, and because of this we have learned many lessons about listening and speaking up.

** To learn more about or to join Self Advocates Becoming Empowered, write to them at P.O. Box # 121211, Nashville, TN 37212-1211.*

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Dybwad, G., & Bersani, H. Eds. (1996). New voices: Self-advocacy by people with disabilities. Available through Brookline Books, P.O. Box 1047, Cambridge, MA 02238-1047. $29.95 Telephone 617-868-0360.

Kennedy, M. (in press). Self-determination and trust: My experiences and thoughts. In D.J. Sands & M.L. Wehmeyer, Self-determination across the lifespan: Theory and practice, pp. 45-46.

Available soon from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624. Stock # 238X, approximate price $35.00. Telephone 1-800-638-3775; fax 410-337-8539.

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MORE THOUGHTS ON SELF ADVOCACY:

The Movement, The Group, & The Individual

BY BONNIE SHOULTZ

Preparation of this article was supported in part by the National Resource Center on Community Integration, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, national Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133D50037. No endorsement by the U.S. Department of Education should be inferred. The Center on Human Policy subcontracts with TASH for space in this Newsletter.

This article discusses individual self-advocacy, group self-advocacy, and the self-advocacy movement. While I will speak from my vantage point as an observer and support person who has fairly intimate involvement with all three types of self advocacy, I want to make clear that these are my own opinions rather than ideas that have been sanctioned or adopted by members of the self-advocacy movement.

The self-advocacy movement is an international civil rights movement led by and for people with developmental disabilities and is one part of the broader disability rights/ independent living movement. It is **international** in many ways. It originated in Sweden in the 1960s, when a group of people with mental retardation labels developed a list of requests about how their services should be provided, and gave the list to the parent organization that supported them. This new idea, that people with these labels could speak for themselves and had something meaningful to say, spread to England and from there to Canada and the United States. Now the movement is alive and growing in many countries. The last international self-advocacy conference in 1993 in Toronto was attended by nearly 2000 people and almost 30 countries were represented.

The self-advocacy movement is a **civil rights movement** in many ways, as well. It is essentially about improving the civil rights of people who have been and still are oppressed, ignored, devalued, and segregated because they are viewed as people who have or are labelled as having developmental disabilities. Much has already been written about this movement: its members and helpers have produced many manifestos, videos, books, manuals, papers, films, and articles. Dissertations and studies have also examined aspects of the movement. Instead of rehashing what is available elsewhere[1], I will describe a recent national conference put on by People First of Oklahoma. This conference — its content and the way it was organized and run — illustrates some of the critical civil rights elements of the self-advocacy movement in general.

Self-advocates and supporters from all over the country were in Tulsa, Oklahoma from August 29 - September 1, 1996 to celebrate their movement, to learn from and share with each other and with nationally known speakers such as Justin Dart, Robert Williams, Tia Nelis, and Gunnar Dybwad, and to elect new members and officers for the Board of Directors of the national organization formed in 1991, Self Advocates Becoming Empowered (SABE). Because there was no more room, registration was closed at 850 participants from almost every state, though more people wanted to attend. The conference included business, politics (national and organizational), music, fun, networking, exhibits, workshops and plenary sessions — all the ingredients that go into any conference.

What was unique to this meeting, however, was the transformative energy and power that could be felt in every plenary session. This energy and power had to do with pride, hope, resolve, and an absolute belief that those present were involved in a cause larger than themselves and could make a difference in the lives of people with disabilities. People who had never before attended a national self-advocacy conference, whether or not they had disabilities, described the experience as "awesome," "eye-opening," "being blown away," and "incredible." It was bigger than any one entity or organization present, but I would like to describe some of the ways People First of Oklahoma and Self Advocates Becoming Empowered contributed to that energy and built it into a palpable force.

People First of Oklahoma worked for the last three years to plan and organize the conference. In the spring of 1993, they presented their bid to SABE to have Tulsa as the site of the 1996 event. People

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First of Oklahoma has a strong organizational structure and is located at the ARC-Tulsa, which provides an enormous amount of logistical and other support to the organization. It had already proved its commitment to the national movement in many ways, and showed the organization that it could host such a conference. Many of the members and helpers in Oklahoma have been involved since the late 1980s, and they have held six state conferences, two of which I had attended. Their state conferences were characterized by many of the qualities that were evident in the national conference — energy, pride, leadership, love and caring, among others.

Doing it themselves is an act of resistance for people with mental retardation and other developmental disability labels, a demonstration that they have and can exercise rights (and capabilities) as citizens. For this conference, People First of Oklahoma members and advisors/support people worked together to ensure that it would be led by and for self-advocates. Every facilitator or moderator on the main stage, and almost every presenter, was a person with a disability (the exceptions were a representative of Tulsa's mayor and a state legislator who has a long positive relationship with the movement). The planning committee had developed a detailed agenda that listed every detail and named the person who would be responsible for it. Thus, when announcements had to be made, the self-advocates responsible had a written account of what they needed to say. When a speaker was to be introduced, a People First of Oklahoma member had worked alone or with a helper to prepare that introduction, and gave it in a polished manner. Moderators or speakers who could not read well were assisted by another self-advocate who could read (typically, People First of Oklahoma President Joseph Meadours, who would whisper the words to the moderator when he or she did not know them). Thus, the self-advocates were truly in charge of their conference.

The content of the conference — the plenary speeches and the workshops — had to do with the current political scene, with issues facing people with disabilities, and with SABE's new campaign for

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institutional closure. Justin Dart and Bob Williams gave rousing speeches that addressed current issues and encouraged people to vote in the coming election. Gunnar Dybwad recalled the history and growth of the self-advocacy movement. Nancy Ward, outgoing Chairperson of SABE, gave an update on the activities of SABE and announced its new membership drive. Tia Nelis, new Chairperson of SABE, invited all present to join the **"Close the Doors Campaign for Freedom"** initiated by SABE, and she and singer Karl Williams led the group in songs and chants about institutional closure. Close the Doors t-shirts, buttons, and notecards were sold, and each attendee received a Close the Doors Campaign packet of tools self-advocates can use to promote institutional closure in their own states and localities.

Self Advocates Becoming Empowered had just received 501(c)3 nonprofit status, and had just begun to separate its financial operations from those of People First of Tennessee, which had assisted SABE with its fiscal management since 1992. SABE's Steering Committee had just become a Board of Directors, and Tulsa was the occasion for replenishing that Board with new members. SABE divides the country into 9 regions, each of which is represented by two people who serve 4 year staggered terms. Thus, every four years regional meetings are held at a national conference to elect one representative to the Board from each region. (A map outlining the regions where SABE representatives are located is on page 24.) Elections for the other representative's position are held at the next conference. Representatives may serve for no more than two 4 year terms. Once it is known who will be on the new Board, campaigning begins for officer candidates, who must be elected Board members.

Election day was a day of high emotions and anxiety. The elections were taken very seriously by a majority of those present, who showed their understanding that they were electing people to represent them at the national level, and that their representatives would be working on serious issues that would affect their lives. The development of this understanding has grown since 1991 when the first elections were held after those present at a national conference in Tennessee voted to form a new national organization. At the 1991 elections, most had little idea of how much work was involved or of how difficult it can be to travel to quarterly meetings where they work steadily for three days and nights, and look for funding to support the commitment one has made in running for representative or officer. In Tulsa, everyone was aware that these elections were significant.

One of the values of the self-advocacy movement has had to do with the necessity to share leadership opportunities with other self-advocates. It can be difficult to do so, because the recognition and opportunity that goes with leadership can be enticing, especially when one knows one has done a good job. At this conference, though, former SABE Chairperson Nancy Ward chose not to run for re-election as Chairperson, reasoning that it was important to adhere to what she believes (she did run for, and was elected as, SABE Secretary). Therefore, the Chairperson position was open and Tia Nelis was elected. Other officers are James Meadours, Co-Chairperson, Theresa Moore, Vice-President, and Debbie Robinson, Treasurer.

Group self-advocacy is another, perhaps the most critical, form of self-advocacy. There could be no national or state self-advocacy organizations without local groups. Self-Advocates Becoming Empowered defines self-advocacy as a group activity:

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Self advocacy is about independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It teaches us about our rights, but along with learning about our rights, we learn about our responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other to gain confidence to speak out for what we believe in.

Self-advocacy groups develop leadership skills and give members the opportunity to get personal support as well as to work on larger issues that affect their lives. The self-advocacy group will usually be helped by an "advisor" but is not directed by its helpers. Instead, it is self-directing, with its activities based on the wishes and ideas of its members.

Because many of the available materials are about self-advocacy groups and their activities, I will do no more here than mention that it is necessary to be clear, when discussing self-advocacy, to distinguish between the movement, group self-advocacy, and individual self-advocacy. Too often, these are confused in the minds of people who are outside of the movement. The confusion is revealed when people with disabilities are uniformly referred to as "self-advocates," and when it is assumed that "self-advocates should ..." get involved in or testify about one or another thing that seems important to people without disabilities.

Individual self-advocacy can be defined in many ways, and one need not be a member of the self-advocacy movement to engage in individual self-advocacy. One way to think of it is as a lifelong personal pursuit of control over one's own circumstances. It is the act of advocating for what one wants, for how one desires to live, for how one wants to be treated, within one's family, community and services, and it does not end with one concession or one victory. It continues, because each triumph creates a new set of issues to be faced. Everyone, whether or not one has a disability, is male or female — whatever one's racial or ethnic identity, whatever other identities one holds — can practice individual self-advocacy. For many people, this practice is almost invisible because it is so taken for granted. For many people with developmental

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Everyone, whether or not one has a disability, is male or female — whatever one's racial or ethnic identity, whatever other identities one holds — can practice individual self-advocacy. For many people, this practice is almost invisible because it is so taken for granted. For many people with developmental disabilities, however, individual self-advocacy is visible and has a heightened meaning.

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disabilities, however, individual self-advocacy is visible and has a heightened meaning. It, or its absence or aberrations, is in the foreground of the person's experience on a daily basis, from moment to moment. Families are learning to promote it by encouraging their family members with disabilities to speak up, to make choices and understand themselves and the world around them.

Service agencies have policies promoting choice and a self-expression. Why? Because until recently, everyone else but the person involved made the decisions, the rules for living, the socio-political culture that encompassed the person's life. The person was taught from birth to comply and thought of as having no voice, no ability to think for himself or to understand the reasons for things. The current emphasis on individual self-advocacy, meager as it is in many places, is meant to correct a grave wrong that has been done to people with developmental disabilities.

The self-advocacy movement, with its thousands of self-advocacy groups, is an underpinning to individual self-advocacy, whether or not individuals who advocate for themselves are members. As a civil rights movement, it provides a context within which individual self-advocacy can operate and succeed. This context has a complex texture.

First, the self-advocacy movement teaches people with developmental disabilities, especially movement members, about their rights and responsibilities as citizens of a society. Members learn ways of understanding and working to correct injustices done them, and they learn positive ways of directing their feelings of anger and fear when they feel oppressed. Second, movement leaders and members exercise their influence in the broader society by meeting with service providers and asking for change, by training employees and family members, by testifying at public hearings and legislative sessions, by writing letters and picketing and attending rallies, by participating on committees, and in myriad other ways. Their actions have changed the service system and families, creating a new awareness on the part of both of the abilities and rights of people with developmental disabilities. Third, they have joined in the struggles of the larger disability rights movement to establish (and to prevent repeal of) laws that protect and support them, such as the Americans with Disabilities Act and the Individuals with Disabilities Education Act, as well as hundreds of laws in individual states.

Self-advocacy, as a movement and as an individual activity, is with us and is making a difference for all of us. It is my dream that some day, the general society will adopt and adhere to some of the values forged by the self-advocates I have known.

[1] *See The Arc Self-Advocacy Bibliography available from Arc National Headquarters, P.O. Box 1047, Arlington, TX 76004, (817) 261-6003 and New Voices: Self-Advocacy by People with Disabilities, 1996, edited by Gunnar Dybwad and Hank Bersani, available from Brookline Books, P.O. Box 1047, Cambridge, MA 02238-1047.*

TASH Newsletter

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